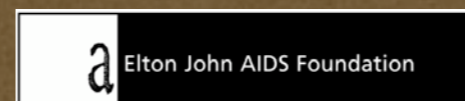


I want to be like the others



**A CROSS SECTOR NEEDS ASSESSMENT OF
CHILDREN INFECTED AND AFFECTED
BY HIV IN SCOTLAND
EXECUTIVE SUMMARY**



FUNDED BY ELTON JOHN AIDS FOUNDATION



Introduction

This report outlines findings from a Cross-Sector Needs Assessment of children infected with, and affected by, HIV in a changed and changing Scotland. New treatments and better support for HIV positive women in pregnancy and childbirth have led to a dramatic decline in the number of deaths from HIV; at the same time, new reports of HIV are on the increase, particularly amongst those whose infections have been acquired overseas (HPS, 2008). The end-result is that more people are living with HIV today, and many more are predicted to do so in the future. And as more adults are living with HIV, so, inevitably, are more children.

The motivation behind this study was the desire of HIV agencies in Scotland to find out more about how HIV is impacting on children in Scotland today; and to develop a deeper understanding of the needs of children affected or infected by HIV. The aim of the Cross-Sector Needs Assessment was therefore to investigate children and HIV from different perspectives: from research and policy documents, from health and statistical services, from a range of practitioners, from parents and carers, and from children infected and affected by HIV. This was achieved through a methodology which encompassed three different strategies: a scoping study, an epidemiological survey, and a qualitative study.

Scoping study

The scoping study identified three different sources of evidence in relation to children and HIV.

- Searches uncovered a considerable body of research which explored epidemiological and psychological factors in relation to children infected with HIV. Notable examples include the European Collaborative Study, which began in 1987 and has continued to provide useful data on infected children ever since, and the Collaborative HIV Paediatric Study and National Study of HIV in Pregnancy and Childhood, which started some years later in 1996.
- There is also extensive 'grey' literature, including government reports, policy papers and agency documents which provides additional information about those infected with, and affected by, HIV, as well as the views of practitioners and those working in the field.
- The views and experiences of children affected by parental HIV have been investigated through a number of illuminative, though relatively small-scale, research projects. Significant examples include the 'Listening to Children in

Scotland' study, conducted between 1999 and 2002 (Cree *et al*, 2002; 2004a; 2004b; 2006; Kay *et al*, 2003; Tisdall *et al*, 2004; Wallace *et al*, 2006); and 'Afraid to Care', on children living with their families in supported housing in London (Lewis, 2001). Additionally, cross-country comparisons of young carers in developed and developing countries (Becker, 2007) and young carers in the context of HIV/AIDS (Evans and Becker, 2007 and 2009) offer further information.

Research on children and HIV demonstrates that, in spite of advances in improved prognosis and treatment, HIV remains a highly troubling and stigmatised illness which impacts negatively on the lives of both infected and affected children. Furthermore, a recent consensus report raises another area of concern, that is, that some 'affected' children may, as yet, be undiagnosed, but infected all the same. Although it may seem that the experiences of children in the UK pale into insignificance as set against the devastation caused by HIV in parts of the developing world, this report demonstrates that the upset which HIV brings to young lives in the UK is real, and its effects cannot, and should not, be ignored.

The scoping study concludes that at a time when the focus of attention is increasingly on the targeted prevention of HIV, and when HIV itself is increasingly being treated as a 'manageable', long-term illness like any other, so the needs of children infected and affected by HIV may become sidelined. This is an area of major concern, not least because HIV, unlike any other serious illness or social issue, remains a secret, uniquely stigmatised and stigmatising condition.

Epidemiological Survey

Infected Children

Evidence from statistical sources and clinicians indicates that numbers of infected children in Scotland are low – between 35 and 47, depending on the method of data collection. Particular issues emerge:

- Thanks to the introduction of HIV testing for pregnant women and successful treatment before and after pregnancy, there have been no children born with HIV in Scotland since 2001.
- It is not known, however, what long-term adverse effects may arise for children of medication taken to prevent mother-to-child transmission of HIV.

- There are now two distinct groups of children infected with HIV in Scotland: younger children (born abroad) and British-born children who are older; born before routine testing and preventive treatment.
- There are special pressures on parts of Scotland in relation to HIV today, with NHS Greater Glasgow & Clyde and NHS Lothian treating the largest number of HIV infected people and young people.

Affected children

Reaching an accurate estimate of children affected by HIV is difficult, because there is no routine data collection. Using methods first employed by Inglis and Morton (1996), questionnaires were sent to key HIV agencies (statutory and voluntary) in Scotland. Overall, 13 agencies provided data about children and young people whom they knew to be affected by parental HIV, and this figure was used to extrapolate for Scotland as a whole. The total number of affected children in Scotland was found to be around 833. Again, mirroring the findings in relation to infected children, specific issues come to light:

- The total number of affected children in Scotland was estimated to be lower than in 1996: 833 as compared with 911 in 1996.
- There has been a shift in pressure on Health Board areas. Tayside today has many fewer affected children than in 1996, as does Lothian (though Lothian continues to have the second largest number of affected children in Scotland). Greater Glasgow & Clyde has many more affected children than in 1996.
- There has been a shift in the age distribution of children, with a much greater number of under-5s in both Lothian and Greater Glasgow & Clyde. There are also many more older teenagers in Greater Glasgow & Clyde, whilst the number in Tayside has fallen. Research suggests that the very young children affected by HIV are largely children of black African mothers, who (it is already known) are living with severe hardships, economically and socially, as well as with HIV (Crusaid/Waverley Care, 2007).
- Most affected children in this survey were not accessing any services in their own right; but were simply known to exist by the agency which was supporting their HIV-positive parent/s. Where services were provided, children made use of them; a small number of affected children were known across three or four agencies.

Qualitative Study

The study identified a range of stakeholders with knowledge and insight into the needs of children infected and affected by HIV in Scotland. Those included:

- Practitioners from health and voluntary sector HIV agencies
- Parents and carers
- Children and young people infected with HIV
- Children and young people affected by parental HIV

In total, 48 people contributed to the qualitative part of the study: 20 practitioners from voluntary sector HIV agencies and NHS services in Edinburgh, Glasgow, Dundee and Aberdeen, as well as 28 adults and children in Edinburgh and Glasgow. Of these, 16 were parents and carers, five were children and young people infected with HIV and seven were children and young people affected by parental HIV. Most interviews were with individuals or occasionally with two practitioners together. One group interview was also held in Glasgow with parents and carers.

Key findings from practitioners

- With the exception of health services, HIV agencies in Scotland are focused on adults; where services for children exist, these have to be accessed through adults first.
- All the agencies currently working with children and HIV would like to be able to do more for children. Additionally, two high profile children's charities (Barnardo's and Children in Scotland) which had been active in the field of children and HIV in the past are no longer involved in this area, because of difficulties in funding this work.
- Agencies work a great deal with others in the field, and with external voluntary and statutory agencies. However, practitioners noted that inter-agency collaboration was made difficult by pressures on agencies, particularly health-care agencies. Concern for confidentiality may also impede collaboration: service users from one agency may not want to be referred to another for specialist support due to fear of stigma.
- Practitioners identified the importance of offering safe, non-threatening services to children infected and affected by HIV, particularly given the stigma which surrounds HIV.
- They also felt that more needs to be done across-the-board to highlight the issues faced by children in relation to HIV (e.g. in schools and in health boards, especially those with low numbers of infected adults).

- A few practitioners spoke about the differences between the needs of young people and those of children, and about the need for a transitional service from paediatric to adult care.

Key findings from parents and carers

- Parents and carers were most concerned about how best to support their child. A principal issue here was disclosure: how, when and what to tell their child and who else could and should be told what, and when. They asked for help to be able to discuss HIV more easily with their children
- Parents and carers spoke about the negative impact of stigma 'by association', and the fear this places on their children. The connection with drug misuse remains a prominent feature.
- They were also all concerned about the lack of services for children infected and affected by HIV, as well as for HIV positive women. It was stressed that giving support to parents may also lead to improvements in children's lives.

Key findings from infected children and young people

- The infected children and young people were at pains to present themselves, their lives and HIV as 'normal'. This was in spite of their very troubled backgrounds and current hardships. Being 'normal' is a major preoccupation in adolescence; it is also, however, an indication of the wish to avoid stigma.
- For some children with HIV, medication is the one reminder that they have the virus; medication also makes them feel ill at times. Because of this, non-compliance to medication in teenage years is not unexpected. The children and young people displayed a knowledgeable and mature approach to their illness, as well as more typically rebellious teenage attitudes at times.
- None of the children was able to talk about their HIV outside a very small, strictly defined zone of safety, for fear of prejudice or reprisal. One child spoke about being unable to talk to the one person who knew about their HIV (the mother), because they did not wish to upset her.
- The children and young people showed ambivalence towards support services. Some did not wish to be singled out for specialist services, because of the need to see themselves as 'normal'. One young person felt that talking about her worries made things worse. All wanted opportunities to have fun and forget their worries, and sport played an important role here. But all also acknowledged that it was good to be able to talk to others in the same position as themselves.

- One youth highlighted the unsatisfactory nature of health provision for teenagers who do not feel comfortable in either children or adult services.

Key findings from affected children and young people

- It was clear from the interviews that parental HIV is something which affects children's lives over and above the difficulties and worries which are commonplace in childhood and adolescence, and over and above any hardships which may also arise out of issues such as poverty, poor housing and insecure immigration status.
- In the same way as infected children, affected children live with fear and uncertainty, never sure when a parent will become ill or die, yet they want to be seen as 'normal' children living with 'normal' parents'.
- All the children could identify someone they could talk to: usually a parent, but also a teacher, youth worker, befriender and social worker were mentioned. But they were very aware of the dangers of disclosing a parent's HIV status.
- None of the affected children and young people in Glasgow was in touch with any support services; all those in Edinburgh were. Again, in common with infected children, they expressed caution about whether additional services would help. They said that support should be available to all children, but they also called for more specialised services so that they could be free to talk about HIV in a safe environment.

Conclusions

- 1) All children and young people affected by HIV (infected and affected children) are 'children in need' under the Children (Scotland) Act of 1995. They have special needs, physically, psychologically and socially. Yet they are barely mentioned in the Scottish Government's draft HIV Action Plan. Moreover, their needs are currently invisible in mainstream, universal, integrated children's services plans.
- 2) Children infected with and affected by HIV do not want to be singled out as different from other children. They want opportunities for education, fun and play like all children, but would also like the chance to meet others in the same situation as themselves, so that they can receive information and support in a safe and secure environment.
- 3) Parents find it difficult to disclose their own HIV status to their children. They also find it difficult to tell their children that they are infected with HIV. Disclosure needs to be handled sensitively; it is not a single event, but is a gradual process

which happens over time, and parents need expert help to support their children better.

- 4) Children infected with HIV are living longer. They have particular needs in terms of health-care and support once they reach teenage years as well as guidance on sex education and relationships.
- 5) The stigma which HIV carries remains extraordinarily high; no other terminal or chronic illness carries such stigma. The cost of this is high for individuals who carry the burden of shame and are unable to share their worries with others. It is also high for society, as those who are afraid to disclose their HIV status may put others at risk, both adults and children.
- 6) HIV in Scotland disproportionately affects families of black African origin who also experience high levels of poverty, discrimination and hardship. Stigma is known to be a particular concern for African people in Scotland, who have little alternative but to keep HIV a secret from others.
- 7) Lothian and Greater Glasgow and Clyde Health Board areas experience high levels of demand generally in relation to infected and affected children, and with particular pressure due to the rise in under-5s affected by HIV.
- 8) There are also small pockets of children affected by HIV throughout Scotland.
- 9) There is currently little opportunity for collaboration across and within Scotland between agencies providing services for infected and affected children.
- 10) There is no routine collection of data in relation to children affected by HIV in Scotland. Moreover, some children may remain undiagnosed and significantly at risk. Government and NHS agencies collect data on infected children in different ways, using different ages as the dividing line between children and adults.

Recommendations

- 1) Scottish Government should re-examine its HIV Action Plan and/or related guidance and implementation to take account of the experiences of infected and affected children.
- 2) Local Authorities should, in turn, be asked to give special consideration to children infected with, and affected by, HIV and ensure their inclusion in their integrated children's plans.
- 3) Financial support should be made available (from central and local government) to voluntary and other agencies to allow them to maintain and extend their specialist provision to children and young people infected and affected by HIV.
- 4) HIV agencies should be funded to provide HIV training and support to practitioners in all agencies which work with parents and infected and affected children.
- 5) NHS Boards should re-examine the provision they currently have for teenagers with HIV, and explore whether an adolescent clinic should be provided in their area.
- 6) There should be a new public health education campaign on HIV. This should stress the reality that HIV can affect anyone, straight or gay; white or black; adult or child.
- 7) More targeted support should be made available to all black African families in Scotland (not only to those where there is known to be HIV), through funding of voluntary and other agencies to carry out this work.
- 8) Additional funding should be made available to areas under greatest pressure from, e.g. dispersal programmes or increased incidence to support their work in this area; at the same time, training on the specific needs of these families living with HIV should be delivered to health visitors and children and young people's workers.
- 9) All Health Boards and statutory children's services should look to see whether more might be done to support children in communities where there are only small numbers of affected children.
- 10) A small sum should be set aside each year to enable one service provider (from a key voluntary HIV or children's agency) to bring agencies together and to act as a national coordinator and champion for HIV and children in Scotland. This could be spearheaded and managed by Scotland's Commissioner for Children and Young People (SCCYP).
- 11) All adults should be asked in a sensitive and supportive way about their parental status (numbers and ages of children) when they are diagnosed with HIV and protocols for testing the children of HIV-positive parents must be worked out in collaboration with patients' and service users' groups
- 12) Government and NHS agencies should reconcile their differences in approaches to data collection in relation to infected children.